

Stories Behind the Symptoms: A Qualitative Analysis of the Narratives of 9/11 Rescue and Recovery Workers

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Abstract A qualitative study of the experiences of rescue and recovery workers/volunteers at Ground Zero following the terrorist attacks of 9/11/01 is reported. Information was extracted from a semi-structured clinical evaluation of 416 responders who were the initial participants in a large scale medical and mental health screening and treatment program for 9/11 responders. Qualitative analysis revealed themes that spanned four categories—occupational roles, exposures, attitudes/experiences, and outcomes related to the experience of Ground Zero. Themes included details regarding Ground Zero roles, grotesque experiences such as smells, the sense of the surreal nature of responding, and a turning to rituals to cope after leaving Ground Zero. These findings personalize the symptom reports and diagnoses that have resulted from the 9/11 responders' exposure to Ground Zero, yielding richer information than would otherwise be available for addressing the psychological dimensions of disasters. This work shows that large scale qualitative surveillance of trauma-exposed populations is both relevant and feasible.

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Introduction

A shared traumatic experience, like the terrorist attacks on the World Trade Center (WTC) on September 11, 2001, has a wide range of not yet fully understood effects on both the individual and societal levels. A variety of research and intervention approaches have been developed for understanding and dealing with the consequences of exposure to trauma. On the individual level, Post-Traumatic Stress Disorder (PTSD) has become the hallmark diagnosis for trauma-related mental health dysfunction. In 1980, an agreed upon definition for PTSD was arrived at and PTSD was included in the third edition of Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-III). The inclusion of PTSD in the DSM-III is widely regarded as a critical moment in the validation of the psychopathological impact that trauma may have on people.

The definition of PTSD has been modestly changed over time. In its current form, PTSD is defined as a cluster of symptoms that are related to “trauma.” A potentially traumatogenic event is defined as one that causes a feeling of intense fear, helplessness, or horror as an individual experiences, witnesses, or is confronted with an event or events that involves actual or threatened death or serious injury, or a threat to the physical integrity of self or others [1]. Following this event, a trauma survivor meets criteria for the diagnosis of PTSD if they have one or more *re-experiencing symptoms* (i.e., nightmares or flashbacks); three or more *avoidance symptoms* (i.e., avoiding reminders of the event, becoming physiologically aroused when faced with reminders, or feeling emotionally detached from people); and two of the possible *hyper-arousal symptoms* (i.e., insomnia or irritability). The definition of PTSD thus hinges on a sufferer dealing with symptoms that are described by themes that fall into three broad categories—re-experiencing, avoidance and hyper-arousal. In brief, they manage painful psychological and physical reminders of the trauma with accommodations to how they think, feel, and behave which, in turn, compromise how they live the rest of their lives.

There is, however, much debate among social scientists about whether PTSD is a construct that adequately captures peoples’ experiences and needs and their surrounding economic and political realities [2]. It has been suggested, for example, that the diagnosis of PTSD focuses too narrowly on medical symptoms within the individual to the exclusion of their social, political, and cultural reality that may be just as central to the experience of trauma as these symptoms [3]. Although these issues are typically raised when discussing application of PTSD in non-Western settings, they do, in fact, come up regularly in Western settings, especially in the clinical practice of psychiatry.

The argument that there is a need to go beyond individual symptomatology in order to understand and treat PTSD is not limited to social scientists. Even among clinicians, therapeutic approaches to PTSD in survivors of trauma goes beyond an emphasis on diagnoses and the PTSD symptoms. While medication is often prescribed to relieve symptoms like hyper-vigilance, irritability, and sleep disturbance, the goal of treatment is also to restore a survivor’s sense of safety, confidence, and meaning [4]. Therapy might include using techniques that facilitate the recall and integration of the memories of the trauma [5]. Post-traumatic symptoms may constitute a final common pathway for layers of personalized and highly individualized meaning which underlie them [6]. While the symptom may be insomnia, for example, the intervention would go beyond standard

treatment to improve sleep and should include raising the question of what goes through the mind of the traumatized survivor when he or she lies awake at night.

It is likely that systematic qualitative evaluation of the experiences of groups of trauma survivors could provide an important window into understanding the trauma outcomes that result and could serve as a guide for interventions. That is, the qualitative description of events is crucial both to the social scientist trying to understand the individual and social impact of the event and to the therapist who is trying to help the individual overcome its aftermath.

A number of published studies have explored the narratives of trauma survivors, encompassing studies ranging in sample size from five to twenty subjects, but including as many as 240 subjects [7, 8]. Among five survivors of an ambush that occurred en route to a Jewish holiday celebration in Israel, investigators found that subjects with narratives of the event which were organized and involved positive self-images did not have PTSD, unlike their counterparts [8]. Following the survivors across three time points up to 4 months after the attack, the investigators concluded that the evolution of a trauma narrative serves as an assay for the person's recovery, as well as indicators for therapeutic interventions.

Investigators interviewed 171 Guinean victims subjected to political violence and atrocities related to upheaval in nearby Sierra Leone and Liberia and found that the nature of the social narrative told by different groups was strongly associated with symptoms of distress, including anxiety and depressive symptoms [9]. Communities whose narrative elements included a sense of resistance to violence appeared to have less symptomatology than communities whose narratives were colored by a sense of disruption, abandonment, and failed resistance.

Gerson et al. [10] conducted individual interviews and focus groups with people who escaped from the WTC on 9/11/01 in order to qualitatively assess the individual, organizational, and environmental factors that affected peoples' ability to evacuate after the terrorist attacks. Investigators identified themes in the recorded transcripts of these interviews and groups, grouped them under one of these factors (individual, organizational, or environmental) and then analyzed whether a given theme facilitated or hindered evacuation. Among the many relevant themes identified were the individual's physical condition; whether that individual had undergone prior drills; and whether they had sensory clues, such as the smell of smoke or feeling the building sway.

Here we report on a qualitative analysis of a large group of 9/11 rescue and recovery workers whose work centered on the site of the former WTC ("Ground Zero"). The data shed light on the actual experiences of 416 workers and supplement our quantitative analysis of symptom counts in that group. The population in the current study is a subset of 1,138 workers whose mental health functioning, as reflected by their symptom scores, have already been reported [11]. In that study we found that 19.7% met criteria for PTSD according to a well-validated and commonly used questionnaire, the Post-Traumatic Stress Disorder Symptom Checklist (PCL; [12]). This was nearly four times higher than the lifetime prevalence that has been reported in the general male population [13]. Major Depression, another common post-disaster diagnosis, was detected at a rate of 5.6% according to the Patient Health Questionnaire [14]. This was less than half of the 12 month prevalence reported in the general population [15]. Rates of alcohol abuse and dependence of 9.4% detected by the CAGE alcohol questionnaire are compatible with the 12 month prevalence of 9.7% reported in the general population [15, 16]. Finally, problems in participants' lives due to emotional difficulties were found to be as follows according to the Sheehan Disability Scale: 13.5% of participants reported problems with

work; 15.3% reported problems in their social life; and 12.9% reported problems in their home life [17].

Other studies have also examined the mental health issues in large samples of WTC responders [18, 19]. Extensive quantitative data on the WTC responders' mental health is therefore available. This paper adds to these findings with qualitative data.

Methods

Sample

Subjects were participants in the World Trade Center Worker and Volunteer Medical Screening Program (WTC-WVMSP), a program established by the National Institutes of Occupational Safety and Health (NIOSH) of the Centers for Disease Control (CDC). This ongoing clinical program provides free medical and mental health screenings for workers and volunteers who participated in the rescue and recovery efforts at the WTC site ("Ground Zero") following the 9/11/01 terrorist attacks. Private philanthropy supported staffing of the medical screening program with mental health clinicians (social workers and psychiatrists) who conducted same day evaluations of patients based on their answers to the mental health screening questionnaires.

The clinical program included an initial screening evaluation consisting of medical- and exposure-assessment questionnaires, physical examination, laboratory studies, pulmonary function tests, chest x-rays, and mental health screening questionnaires [11]. Initially, participants were recruited through outreach that included community and union meetings, mailings, and articles in the media. Eligibility criteria were defined as a minimum of 24 h working/volunteering during September 11–30, 2001, or >80 h during September 11–November 30, 2001, either south of Canal Street, the Staten Island landfill (Fresh kills), or the barge loading piers. Employees of the Office of the Chief Medical Examiner were also eligible, regardless of hours worked. FDNY and State of New York employees had access to other screening programs and were not eligible for this program.

The mental health assessment included previously validated quantitative surveys about general psychiatric distress, post-traumatic stress disorder (PTSD), major depression, alcohol use, and disability. The patient completes the questionnaire upon arrival for the medical screening and their responses are immediately evaluated. If a patient's responses to any of the measures were above a pre-set value, the patient was considered to have "screened in" and was invited to undergo a semi-structured mental health evaluation geared at elaborating on their written answers and clarifying the severity of their mental health problems and their relation to 9/11. The ultimate goal of this evaluation was to determine the need for referral to ongoing care. Information from this evaluation was recorded in the Clinical Evaluation Record (CER). Full details of the screening process and of the CER's development and implementation are available elsewhere [20].

The CER guided an open-ended interview meant to complement the close-ended questionnaires (i.e., if the person screened in for PTSD, the interviewer was prompted to ask, "*Here you circled that you experienced 'x'. Can you give me an example?*"). Clinicians (social workers or psychiatrists) were instructed to record replies to the interview questions as thoroughly as possible without compromising their interaction with the patients. This paper reports on the information collected in the initial 416 CER's completed when the program began on July 16, 2002 and before close-ended modifications were added to the CER in November, 2002. This analysis was conducted with the approval of

the Human Subjects Committee of the Mount Sinai School of Medicine and the Patient Protection Committee of the WTC Medical Monitoring Program (New York, NY).

Qualitative Analysis

In order to permit analysis of the narrative information that was collected, two of the investigators transcribed the handwritten narrative data from the initial 416 CER's under the supervision of a senior investigator. This transcription included removing identifiers (e.g., medical record numbers) from the data and assigning subject numbers.

Another investigator, who was also the lead developer of the CER, next read the transcribed narratives in order to identify potential themes or trends within the material. Among the questions that were posed to patients in the course of completing the CER, one was "What was your role?" It was found that a significant amount of information was recorded in the CER of 413 patients in answer to this question.

This unexpected finding tended to encompass a broad amount of information about the responders' experience working in the rescue and recovery efforts at Ground Zero beyond a simple description of what they did. No other questions (e.g., "Where were you when you first learned of WTC attacks?") generated nearly as much recorded information. This investigator identified a number of recurrent themes in the narratives, and the two transcribing investigators reviewed these themes in order to add other themes suggested by their transcription. This led to a list of 18 themes (e.g., distress over the smells at the site).

All of the investigators next met to re-examine the 413 available narratives for the question, "What was your role?", according to these 18 themes. This permitted the option of further adding previously un-identified themes. The investigators also organized the themes into broad thematic categories.

Two of the investigators returned to the narratives and separately ranked each subject according to whether they endorsed any of the identified themes. They next discussed their categorization and resolved differences, which were rare. All investigators then met again and reviewed the findings, ultimately agreeing that sufficient consensus had been reached on the breadth and occurrence of themes.

Analysis of this final data included examination of the frequency of themes as well as of potential variation in the amount of narrative information recorded by each clinician. Salient quotes from within the original narratives were extracted in order to exemplify some of the more frequent themes.

Results

Table 1 provides demographic data on the study population, which was only available for 402 of the patients.

Table 2 shows the final consensus themes identified within the narratives of the 413 patients for whom narratives were recorded for the question "What was your role?" and the four broad categories in which these themes were organized: (1) occupations or activities at Ground Zero; (2) nature of exposure to 9/11 at Ground Zero; (3) attitudes/feelings about their activities at Ground Zero; (4) outcomes in the lives of the responders following their work at Ground Zero (Table 2).

Table 1 Demographic characteristics of WTC Mental Health Program participants, from June to August 2002 ($N = 402$)

	No. ($N = 402$)	%
Age		
Mean (SD)	42.72 (9.56)	–
Median	41.9	–
Gender		
Male	363	90.3
Female	39	9.7
Marital status		
Single	84	20.9
Married	252	62.7
Separated/Divorced	41	10.2
Widowed	4	1.0
Unknown	21	5.2
Race/Ethnicity		
Black	57	14.2
White	269	66.9
Hispanic	63	15.7
Asian	5	1.2
Other	8	2.0
Union membership		
Non-member	46	11.4
Member	352	87.6
Unknown	4	1.0
Education		
Less than high school	20	5.0
High school	100	24.9
Some college/technical school	170	42.3
College	49	12.2
Graduate education	31	7.7
Unknown	32	7.9
Occupation		
Technical and utilities	138	34.3
Construction	73	18.2
Public sector—blue collar	70	17.4
Law enforcement	33	8.2
Miscellaneous	29	7.2
Transportation	23	5.7
News agencies	15	3.7
Health care	7	1.7
Volunteers	5	1.2
Firefighters	4	1.0
Office/Admin/Professional	4	1.0
Cleaning/Maintenance	1	0.2

Table 2 Themes grouped according to major categories of exposure, activities, and attitudes and feelings at Ground Zero and personal outcomes and responses to this work

1. Roles & occupation <i>Did the person describe activities or duties related to 9/11 whether at or around the site or at some alternate location related to 9/11 work (e.g. Freshkills, morgue)?</i>	2. Exposures <i>Did the person describe exposures related to the initial events of 9/11 or to their work?</i>	3. Attitudes & feelings <i>Did the person describe attitudes or feelings about their experience(s) around 9/11, their work thereafter or reactions after leaving the site, including:</i>	4. Outcomes & responses <i>Did the person describe any outcomes and responses that were a result of or reflective of the events of 9/11 and work related activities, including:</i>
<ul style="list-style-type: none"> • What were those activities as recorded verbatim? • Was time spent at the site(s) volunteered? 	<ul style="list-style-type: none"> • On 9/11, was the person <ul style="list-style-type: none"> – On site—was the person at the WTC site for work related activities? – Survivor—was the person in/around WTC at the time of the events. Did they acknowledge fleeing for their life? – Witness—did the person visually witness the events of 9/11? – Fear for their life—did the person express an immediate fear for their life? • Physical environment—did the person remark on the physical environment at the WTC site, including? <ul style="list-style-type: none"> – Smoke/dust—did the person remark on air quality? – Hours of Work—did the person speak about long hours worked? <ul style="list-style-type: none"> Initial—did the long hours last <1 week, or: Continuous—did long work hours persist for a long period of time (>1 week)? – Body parts—did the person witness body parts? – Smells—did the person remark on smells? – Pile—did the person work on or was exposed to the 'pile'? – Personal affects—did the person notice personal effects—such as shoes, purses, jewelry, toys? • Psychosocial environment—did the person comment on any elements of the psychosocial environment, including? <ul style="list-style-type: none"> – Pressure—did the person feel pressure from authority, supervisors or co-workers? – Turf war—did the person remark on feuds between groups of workers or individuals? – Disorganized—did the person find the work or systems governing work disorganized? – Camaraderie—did the person bond fellow co-workers? – Lack of supervisor support —did the person find that authority did not properly support them or fellow co-workers? – Personal loss—did the person experience a personal loss associated with 9/11 (e.g. death of friend or family)? • None Described—did the person specifically note "not" being exposed? 	<ul style="list-style-type: none"> • Personal danger • An inability to leave the site • Wanting to block events out • Not wanting to be there • Altruism • Needing a break • Pride and or a sense of accomplishment • Futility • Isolation • Helplessness • A sense of disbelief or that the events were surreal • Empathy • Grief • Less secure • Anger and/or negative feelings • No attitudes or feelings were expressed 	<ul style="list-style-type: none"> • Emotional symptoms • Physical symptoms • Left site • Treatment seeking • Rituals—e.g. anniversaries, ceremonies • Took break • Denied treatment • None described

Occupation/Activities

Of the 413 responses, 342 described their work at Ground Zero in their narrative. Individuals described a number of different duties that provided details beyond those available from occupational title alone (Table 3). Activities occurred during relief operations, when efforts focused on rescuing survivors, and recovery operations, when rescuing gave way to finding bodies and personal belongings.

The greatest number of individuals (70) reported running cables and lines to repair phone and communications service. Individuals also reported working on demolition, clean-up and the bucket brigade (i.e., relaying recovered body parts and belongings) in large numbers. Other reported activities included: trucking and transport, landfill and sanitation work, search, rescue recovery and triage, digging, security, building and construction, or working for EMS/EMT, the Fire Department of New York (FDNY), or the New York City Police Department (NYPD). A number of individuals also indicated which company they worked for. When noted the vast majority spoke about working for the telephone company ($n = 21$). Thirty respondents identified themselves as volunteers at the WTC site.

Exposures

Of the 413 transcribed responses, 285 (68.3%) individuals talked about direct exposures they experienced as a result of the WTC event. The descriptions ranged from exposures experienced from the first plane hitting the North Tower at 8:46 am to exposures arising from the rescue operation or the recovery phase (Table 2).

Many workers witnessed the attacks firsthand, an indication that they were in the vicinity of the WTC (Table 3), while a smaller number ($N = 10$, 2.4%) were actually at the WTC (“on site”) at the time of the attack. Several individuals also made comments that relate to a “survival response,” with 23 (5.6%) responses referencing some element of being a survivor and 13 (3.1%) indicating that they feared for their life.

During the recovery phase exposures primarily fell into one of two categories, those related to the physical environment and the psychosocial environment. Themes of the physical environment include: smoke and dust exposure, long hours worked, bodies, smells, the pile or rubble and seeing personal items or artifacts of individuals at the site. Themes specific to psychosocial exposure include: feeling pressure from supervisors and lack of supervisor support, turf wars between groups or individuals working at the site, disorganization, camaraderie and personal loss.

Nearly half of workers commented on the physical environment. The sight of bodies factored into many responses: “[I] put bodies into body bags. Worked with [my] hands. Seen expression on faces of people buried alive.” Several went further commenting on the emotional response to seeing bodies.

I went to see a friend, had my tools, and got recruited. The two cops found alive in the hole...the only 2...I was part of the crew that pulled ‘em out. One guy was pinned—it took us 6 hours to get him out, he was ok. I was pulling out body parts...it was awful...the first body I pulled out was of a women, 8 months pregnant...with no head. I still have nightmares. I have the nightmares every night...wake up 15–20 times a night. I know 16 who died down there, people I grew up with.

Another worker also drew on the effects that seeing dead bodies had on him: “Looked for body. Not good. Never found my uncle’s body—but found [another] body. It’s always

Table 3 Frequencies of themes endorsed within the clinical evaluation records of ($n = 416$ total subjects)

Categories	<i>N</i> (413)	%
<i>Roles & occupations</i> ^a	342	82.8
Ran/repair cables & lines	70	16.9
Clean up & demolition	43	10.4
Bucket brigade	34	8.2
Other	22	5.3
Trucking & transport	21	5.1
Verizon employee	21	5.1
Landfill & sanitation	18	4.4
Search, rescue, recovery & triage	16	3.9
Digging (on pile)	13	3.1
Security	12	2.9
Building, maintenance & construction	11	2.7
EMS/EMT	10	2.4
Reporter, video, artist	9	2.2
Lighting, power & electric	9	2.2
NYPD	9	2.2
Morgue & medical examiner	9	2.2
Supervisor	8	1.9
Iron worker	7	1.7
Food, shelter & supplies	7	1.7
Health worker	6	1.5
Emergency services (FEMA)	5	1.2
FDNY	5	1.2
Evacuation & escort	4	1.0
Equipment set up	4	1.0
Con Edison employee	3	0.7
Barges & piers	3	0.7
<i>Exposures</i> ^a	285	69.0
Exposures to events of 9/11	68	16.5
On site	10	2.4
Survivor	23	5.6
Witness	63	15.3
Feared for life	13	3.1
Physical environment	202	48.9
Smoke	45	10.9
Long hours	92	22.3
Initial hours long	21	5.1
Continuous hours long	28	6.8
Hours unknown	42	10.2
Bodies	107	25.9
Smells	44	10.7
Pile & rubble	14	3.4
Personal things & artifacts	13	3.1
Saw nothing	20	4.8

Table 3 continued

Categories	N (413)	%
Psychosocial environment	114	27.6
Pressure from supervisors	4	1.0
Turf war	2	0.5
Disorganized	38	9.2
Camaraderie	40	9.7
No supervisor support	17	4.1
Personal loss	36	8.7
<i>Attitudes & feelings^a</i>	167	40.4
Personal danger	15	3.6
Unable to leave	9	2.2
Block out	25	6.1
Wanted to leave	8	1.9
Altruism	16	3.9
Need break	8	1.9
Pride	14	3.4
Historical	1	0.2
Futility	5	1.2
Isolation	7	1.7
Helplessness	12	2.9
Surreal	29	7.0
War	13	3.1
Empathy	27	6.5
Grief	11	2.7
Less secure	11	2.7
Anger & negativity	27	6.5
<i>Outcomes & responses^a</i>	132	32.0
Emotional symptoms	93	22.5
Physical symptoms	21	5.1
Left site	20	4.8
Treatment	18	4.4
Discord	11	2.7
Rituals	12	2.9
Took break	5	1.2
Denied treatment	25	6.1

^a Total represents individual who remarked on any of the more specific categories. Number do not necessarily equal totals as individuals could indicate multiple occupations, roles, exposures, attitudes and feelings and outcomes and responses

in my head.” The enormity of the experience was even mentioned by those with past experience working with human remains. A medical examiner noted:

Body IDs/x-rays of remains/assisted and worked with medical examiner. Worked on homicides for many years, but never saw anything like this. Beyond anybody’s imagination. Lost some friends in WTC. I put myself into work mode. Looked at it as a function. Bodies uncovered looked like mummies. Work felt very chaotic. Everybody working under their non-organization...fourteen-sixteen hour shifts and then volunteering in extra time. Bucket Brigade. 4 hours sleep. Also had to work at plane crash site in Queens—easier than WTC ‘cuz actually found intact bodies.

Many also drew a connection from the bodies (that they saw during the recovery effort) to the act of jumping from the windows. One worker remarked at how terrible the site was:

[I] was working in the morning, went to get coffee with co-workers when the first plane hit the buildings. [I] knew right away that it was not an accident. [I] saw people jumping down, which was the most disturbing thing he ever saw. [I] tried to make his way home as soon as he could to meet his wife, who was 7 months pregnant at the time. Next day [I] went to work for Verizon and was shocked by the level of distraction.

Smells also elicited a strong response. Several made the connection between seeing bodies and the overwhelming smells:

Job called and said to report to work. Like a nightmare when came out of the tunnel from NJ. Fueling equipment. Worked 18-hour shifts. Then working on barges at landfill. Saw body parts, the smell of death everywhere. Working in chaos and mass confusion.

A quarter of individuals also commented on the long hours spent working at the WTC site. For some the decision to work long hours was completely voluntary, as many felt it difficult to leave emotionally. Others felt pressure from their supervisor to stay.

Fewer narratives noted the pile specifically. But the pile and rubble of Ground Zero were mentioned by 14 (3.4%) respondents. Experiences of working long hours and of the rubble was described by the following volunteer firefighter:

Volunteered as a firefighter. Main concern was rescue on the first day. One of the first people to stand on the rubble. Like a dream! Worked first 4 days continuously. Rescue and sanitation duties. Saw body limbs and parts. I was detached from what I was seeing to do job.

Several (4.8%; $N = 20$) felt it necessary to remark that they saw nothing at the WTC, in many cases indicating that they saw nothing “traumatic,” particularly “dead bodies”.

Psychosocial exposures were mentioned by 114 (27.3%) of workers, about half as often as physical exposures. Approximately equal numbers of workers mentioned disorganization (9.2%; $N = 38$), personal loss (8.7%; $N = 36$) and the more positive aspect of the recovery effort: camaraderie (9.7%; $N = 40$).

The disorganization that prevailed at the recovery site was a source of frustration for many. One respondent commented that supervisors “did not know what to do with us.” Others described conditions as “chaotic” or “like a madhouse.” One worker who provided “security around site. Escorts of family members,” called the situation “organized mayhem. No clear-cut duties.”

Many members of the study population lost family members, friends and co-workers:

Stayed at Ground Zero 24/7 for 1st week. Passing buckets of debris pile. Lost 54 firefighter friends. Gave up hope on Saturday. Looking for friends. Part of 3-person team who told family members about deaths.

Positive aspects of the experience were also reported, including camaraderie or bonding. One individual described his work thusly:

Worked at a small Salvation Army canteen on Church Street. Being friend to the guys. [We] became a family. Workers could hang out in the tent. Went into emotional

shock. Hid behind camera for a week. Worked 4 PM-6 AM. Worked overnight through January. Cough got worse in January...I need a break from life right now...it's been difficult to leave the camaraderie and close-knit world of the site.

Others indicated that they felt supported or that they made friends with many at the site. Some also indicated that their fellow co-workers were the only people on whom they could rely or who understood them and their situation, thus bringing them closer together.

Worker responses were not uni-dimensional and many commented on various exposure themes at once, illustrating the complexity of exposures at the WTC site:

No function at the beginning of 9/11. Worked on the pile. Bucket brigade. Smell overwhelming. Picked up body parts. Worked 16 hrs/day/month. Very little sleep. Camaraderie amazing. Emotional part was harder than the physical part. Lost 7-8 lbs during the time. Post was at Fulton and Broadway entrance. Felt like a counselor but wasn't trained for it. Couldn't cry in front of people. Worked straight through for 3 weeks. Felt guilty leaving the site. Felt compulsion to be there. Felt so good when people came up and said thank you for what you're doing.

Attitudes/Experiences

We generated a list of themes related to worker's attitudes and feelings at Ground Zero: in personal danger while at the site; unable to leave the site; blocking out the emotional or disturbing aspects of the recovery work; desiring to leave the site; a sense of altruism; needing a "break from life"; pride in one's work; seeing the recovery effort as a "historical" event; futility (meaning the recovery effort was not saving anyone's life); isolation; helplessness (meaning one couldn't properly contribute to the effort); the "surreal" nature of Ground Zero; likeness to war; empathy with families; grief for family, friends, or co-workers; feeling less secure against future attacks; and anger and negative feelings regarding recovery work (Table 2).

Thirteen workers (3.1%) made some comparison between Ground Zero and a war zone or battlefield. Said one, "Picking up body parts and taking them to temporary morgues. Worse thing I've ever seen and I've been in combat." Another said, "[Am] a Vietnam Vet and states 9/11 exposure to sights of Ground Zero was worse than Vietnam." Similarly: "It looked like a war scene. I was a marine in the Persian Gulf, so I have had some exposure to scenes like Ground Zero." Lastly, "Looked like a battleground. Was in Vietnam. Marine corp. Flashbacks of Vietnam."

Twenty-nine workers (7.0%) made reference to the "surreal" nature of Ground Zero. The terminology used to describe their surroundings was vivid and textured: one worker said it "[w]as like living on another planet—smoke, dark, chaotic, 'gray snow'." Another said it was "[l]ike a Godzilla movie." According to another, "[i]t was an 'unearthly' experience." Workers also described Ground Zero as "like being inside a black and white TV" and "unrealistic, like a movie set." Other descriptions were more graphic: "Saw entire jet engine, arm, leg—No way of escaping it—felt Armageddon—Pools of blood, arms, legs."

Twenty-seven workers (6.5%) expressed angry or negative feelings regarding their recovery work. Several workers commented on their anger towards those who sought to profit from 9/11:

[I] set up a food area at Bowling Green—spent 20K—got a plaque for it...All those guys down there making money...It bothered me. Contracts? For tragedy... I worked for nothing—couldn't accept a penny.

Another worker expressed anger regarding the “hero” role:

It was weird driving down Hero Highway...Plying me with sandwiches for doing what I was doing...It doesn't feel right to get recognition... You want to say thanks—on the other hand—get the fuck away.

Conversely, some workers felt that they were denied the role of hero:

I feel angry that the event happened. The worst for me has been the concept of hero – I think we all are heroes – not just firefighters/police. I feel unappreciated.

Other workers were angry about their perceived mistreatment by their boss, or by the city. One worker said:

the [Transit Authority] were the first people to go – the group mobilizes heavy equipment – all we got was a letter – the way Giuliani treated us. I mean just because nobody dies – doesn't mean we did nothing.

Another worker complained that there was “no-one to say goodbye. Just walked off the site. No goodbye. Anger, resentment. Courtesy, pity. Stayed little too long. Didn't get invited back for ceremonies.”

In contrast to those responses, many workers expressed positive attitudes and feelings about their recovery work. Several ($N = 14$, 3.4%) expressed pride in their work. One worker said: “We took over a room in the embassy suites to sleep a bit ... I'd go home ... Each day ... I could sleep OK ... No nightmares ... I thought we were doing god's work.”

Another worker said simply, “I hope I never have to smell that smell again. But the spirit of people. I am so proud.” Sixteen workers expressed a sense of altruism, such as the worker who said he was “motivated to work, to help get NY back on its feet.” Another worker said he was “physically drained but couldn't stop. Felt in personal danger the whole time he was there but didn't think of himself, only others.”

Outcomes

Responders also spoke about how they coped with their work at the WTC site. The following outcomes were described by workers: emotional symptoms; physical symptoms; sought out or accepted mental health treatment; denied or refused mental health treatment; left the site (voluntarily or involuntarily); “took a break” from life; experienced discord in personal relationships; and observed rituals pertaining to the memory of September 11 (Table 2).

Ninety-three first responders (22.5%) described emotional symptoms they experienced as a result of 9/11, and 21 (5.1%) mentioned physical symptoms (Table 3). (For the purpose of this analysis, we considered any symptom having to do with altered sleep as emotional, rather than physical.)

One worker responded with the following:

It's very hard...actually, to talk about it. I know I will do it, it's your job and you are here to help...the hardest thing? I see it all again, sometimes. Every day, at least once. Once I stopped sleeping, it got much harder. Actually I can't remember when I stopped totally being able to sleep. I sleep 2 hours a night. At first it was different, now—I toss and turn all night, it's awful. I can't think or concentrate at all. I am terribly irritable. Got in a fist fight yesterday with someone who was winding me up. I suddenly snapped. I'm not like this. I've never been this way before. I could always

sleep it off; my nickname is _____. I feel like I'm going crazy inside. I have these panic attacks. I don't want to be dramatic but it feels like I'm going to die. I have felt stress before. But nothing like this ever.

Another worker, whose response was transcribed in the third person by the interviewing clinician, was described as:

field technician who was at work in midtown when she first learned of the attacks. Pt was then transferred down to the WTC on 9/13 until mid December. Pt discussed great difficulty in coping with the work she did at ground zero. Pt discussed increase depressed mood, increase anxiety, increase irritability (losing her patience with friends and boyfriend, lashing out violently: hitting with hands and phone/objects), difficulty sleeping, and frequent panic attacks.

Certain workers reported that their emotional symptoms surfaced only after they left the site: "[The patient] discussed that he didn't have any difficulties during the 8 months that he worked at ground zero, but when he stopped working at ground zero he began to feel increase anxiety, lethargy, increase irritability, and decrease pleasure in doing things. [The patient] had a friend who died in the attacks."

Twelve workers (2.9%) mentioned rituals regarding 9/11. Funeral attendance was not counted as a ritual but special references to 9/11 anniversaries or efforts to memorialize the day with events were. Several workers mentioned getting tattoos as a way of memorializing 9/11: "I got this tattoo...in December (Sept 11 eagle)...I'd been so angry...felt so bad...for me, it's closure..."

Another said he got a tattoo on 9/11/02: "went with 25 firemen 'never forget.'" Workers described an increase in symptoms around the first anniversary of 9/11: "Funny around the anniversary, I couldn't sleep."

Eleven workers described discord in their family or personal relationships that they attributed to 9/11. This was described in frank terms by one worker: "The anniversary...I was scared. My wife's birthday is Sept 11. She moved out last year...left me when I was on the pile...we'd been having problems...but honestly I was so numb I didn't care."

Another said:

While I was at work on the pile or at the morgue...I got along and did extremely well – didn't have to think about any of the problems of life. When I got out of there – that's when the trouble starts. Yeah I was able to sleep. I have a small NYC apt. A sublet...My partner finally came in after two days though she was scared...I only felt ok at the site. So I began lying...My partner would say what about us...but I didn't want to be there. Four years with her...We separated a month ago.

Another described the toll her emotional symptoms took on her relationship: "[The patient] reported having "a lot of difficulties" since 9/11 including increased anxiety, increased irritability, panic attacks, restlessness, and difficulty sleeping. These [symptoms] have affected her relationship with life-in girlfriend – currently in couple's counseling."

Conversely, a few of the workers described the opposite effect: they mentioned ways in which 9/11 strengthened their family relationships. One CER documented, "[The patient] reports his family has been closer since 9/11." Another worker echoed this sentiment: "I have been with my wife x 27 years ... I know what I have ... Didn't need 9/11 to appreciate her. But it makes you appreciate how lucky you are even more."

Discussion

The qualitative responses that we have reported in this paper are drawn from the subgroup of all patients who “screened in” to a clinical evaluation and add meaningful detail to the symptoms and diagnoses that we and others have already reported for the first 1,139 WTC first responders [11], and for larger groups of 28,962 responders [18] and 10,132 responders [19]. To the best of our knowledge, this study reports on qualitative findings in the largest published sample of trauma survivors.

The criteria for PTSD include distressing recollections of “perceptions.” The analysis presented here has helped us to better understand and define those perceptions. The qualitative analysis that is the bedrock of much social science research has added “poetry” to the systematized pre-categorized “prose” of standardized survey instruments and diagnoses. For example, the standard 17-item checklist for PTSD, the PCL [12] has five items to define re-experiencing symptoms. The present analysis provides insight into the content of those experiences, and we are able to ascertain that for many of the responders re-experiencing included not just the sight of bodies but also the smells of the site. Further, it is interesting that re-experiencing for many of the respondents referred to an exposure that they never actually experienced themselves: seeing bodies or body parts. It may well be that the anticipation (e.g., fear of the possibility) of the experience of coming across a body was itself traumatogenic.

Likewise, the narratives conveyed how the long hours of work, disorganized work conditions, and pressure from supervisors at Ground Zero were among the psychosocial factors that contributed to the distressing nature of the responders’ experience. The impact of working conditions or other psychosocial factors on PTSD is not part of the PCL’s general symptom list. This finding reinforces the idea that the current medical model for PTSD does not tap into the full range of exposures and responses related to the disorder. Further, it reminds us that seemingly mundane aspects of disaster exposure, such as the structure of the work environment, should not be overlooked among the more dramatic elements such as exposure to bodies. In fact, working conditions, while necessarily chaotic amid disaster, are none-the-less a potentially modifiable factor for future events. It is also important to note that post-disaster interventions may also be necessary, as in one respondent’s description of what it was like to leave the disaster site as, “[j]ust walked off the site. No goodbye.”

While it is of course a truism to say that each person will have had a uniquely personal experience of Ground Zero, that population-based research requires the development of standardized instruments or that clinical treatment requires systematic diagnostic criteria, it is also important to remember that qualitative data, such as those presented here, provide a rich weave to the strands of epidemiological information garnered from standardized interviews and surveys. The depth of meaning and experience amongst survivors of trauma is usually left for clinicians to address as they wade through the morass of trauma with their individual patients. Our findings suggest that the breadth and depth of personal meaning can be identified by epidemiologists and social scientists at the level of the community of survivors and, in so doing, our professional understanding of, and preparation for, trauma and disaster can be more fully enriched beyond the medical framework defined by the DSM and beyond the consultation room.

The ad hoc nature of our qualitative analysis constitutes a limitation of our study. Because the mental health screening method of the WTC-WVMSP was not designed as a population-based study, but rather was a clinical intervention, we have, of necessity, departed from typical qualitative analytical methodologies. Further, the population comprises a convenience sample and we have no way of knowing the extent to which our findings are

generalizable to the entire population of WTC first responders or to disaster responders in general. However, the comparatively large sample size and the consistency of responses do give us some confidence that these findings are generalizable beyond the sample itself.

The categorization of findings into four broad areas—activity, exposures, attitudes/experiences, and outcomes—may also have compromised the very element of individuality that we are suggesting qualitative analyses can provide. There is the risk that these categories might fail to capture the true range and breadth of the qualitative data. It is possible that other researchers might generate different themes from among our qualitative data and yet a fuller picture would still emerge.

Despite these limitations, the qualitative findings presented in this paper demonstrate that the nuance of personal experience in a traumatized population that screening and diagnostic surveys necessarily miss may still be captured on a large scale. Qualitative data enriches quantitative findings, permitting clinicians and emergency response agencies to better anticipate and respond to the human experience of future disasters.

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